Other formats:

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team:

patient.information@addenbrookes.nhs.uk.

Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site.

For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Department of Gastroenterology

Patient Information

After Your Transplant

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Following your transplant

You are likely to be in hospital post transplant for at least two to three months and may be in for considerably longer depending on your progress. In these first few weeks we describe it as “The transplant roller coaster” as you may well have “good” days and “bad” days.

The intensive therapy unit (ITU) and high dependency unit (HDU)

After the transplant operation you will be taken directly to the intensive therapy unit (ITU), where you will be looked after by doctors and nurses who are specifically trained and experienced in looking after patients post transplant. The gastroenterologists, surgeons and transplant specialist nurses will also be closely involved in your care.

You may also have a tube in your wind pipe to assist your breathing until you are more awake and able to breathe completely on your own. The tube is attached to a ventilator which helps your lungs expand.

You will have many intravenous lines in place when you first return from the transplant. These are for giving intravenous fluids and drugs and giving or taking blood which assist the nurses and doctors looking after you in the immediate period following the transplant.

There will also be a tube called a naso-gastric tube, which is inserted via your nose (whilst you are under the anaesthetic) into your stomach to drain fluid from your stomach, which will stop you feeling nauseated. Once the doctors are happy that your bowels are starting to work the naso-gastric tube will be removed.

<table>
<thead>
<tr>
<th>Checklist before setting off from home</th>
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<tbody>
<tr>
<td>Ring the ward to see if a bed is available the morning of admission. <strong>You will be advised of what ward you are being admitted to on your admission letter but if you are unsure please contact the small bowel transplant nurses.</strong></td>
</tr>
<tr>
<td>Bring all medications with you</td>
</tr>
<tr>
<td>If on PN bring three days’ supply with you</td>
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**Please feel free to use this space to write any questions for your transplant specialist nurses or doctors...**
Keeping in contact with the team
The small bowel transplant nurses are your first contact point.

In the early days post transplant you will be in contact with the team frequently (perhaps up to twice a week) but as your condition improves this contact will lessen. It is important that you let us know as soon as possible of any changes in your condition so that we can act upon them promptly.

If you need to speak with a member of the team urgently you should call switchboard on 01223 245151 and ask to speak with the Transplant Surgical Registrar On Call.

Privacy & Dignity
Same sex bays and bathrooms are offered in all wards except critical care and theatre recovery areas where the use of high-tech equipment and/or specialist one to one care is required.

You will have a catheter going into your bladder to drain your urine, which is measured regularly to ensure that your kidneys are functioning well. This catheter can be removed when you are more mobile.

Biopsies will be taken via your new stoma very regularly to monitor for signs of rejection in the first few weeks. These will gradually get less as time goes on. If any signs of rejection are seen you will be given anti rejection drugs and your progress monitored.

Nutrition
You will have parenteral nutrition (PN) for the first few days post transplant until the team is happy your organs function and then as soon as possible you will be fed via a tube directly into your bowel and then by mouth.

Once we are happy with your progress and you are eating, drinking and feeling a little more independent you will be transferred to the transplant ward to prepare for your discharge home. Here you will be taught about looking after your transplant and about your medication.

Pain relief
We are aware that pain has often been a big problem for a long time for our pre-transplant patients and that many of our patients are regularly taking very strong pain killers. We are aware that it can sometimes be difficult to control post operative pain easily. For this reason during your assessment we will look at your drug requirements pre-transplant and discuss this together with you and the pain team so that a plan can be prepared as to what your requirements are likely to be post transplant.
Our studies have shown that not all patients are pain free long term post transplant but we would hope that for most there is a reduction in the abdominal pain that they experience long term.

What will be expected of you when you are discharged from hospital after transplantation

Regular hospital visits
Once you have been discharged from hospital we will need to see you on a very regular basis until we are happy that you are coping at home and stable. You will need to come back to the hospital for:
- Regular biopsies of the new bowel
- Medical reviews
- Nutritional reviews
- Blood tests
- Investigations

These visits will get less frequent until hopefully you will only need to be seen about every four to six months. It may be possible to set up a shared care arrangement with your local team that referred you initially. We will also work closely with your GP and expect you to see them for non transplant related issues.

Readmission to Addenbrooke’s Hospital
It’s not unusual for small bowel transplant patients to have to be admitted into hospital from time to time after their transplant. This may be to monitor blood results, for intravenous fluids, antibiotics or managing a change in medication. Your coordinator will arrange this for you.

Post transplant complications
Patients must take anti-rejection drugs to suppress their immune system so their body will accept the transplanted bowel. They must take enough drugs to prevent rejection, but not too many or they may have problems with infection, kidney problems and drug toxicity. Prograf® (also called FK506, tacrolimus) is the most common anti-rejection drug used in intestinal transplantations.

After intestinal transplant you may experience postoperative complications. Because of the high doses of immunosuppressive medications, intestinal transplant recipients are at higher risk of infection compared to other surgery patients. Rejection is another complication in which the body reacts against the transplanted intestine. Intestinal ischemia (lack of blood supply to the organ) and leaks can happen due to surgical technical difficulty in reconnection of the intestine and the vessels.

There are treatment options for all of the above-mentioned complications but in some cases they result in organ loss or even death of the patient.

Further information will be provided in the post transplant information book but the transplant nurses, gastroenterology and surgical teams will be happy to talk through these with you should you wish.
We would expect this to improve over the first one to two years as you begin to adapt to your new life following transplant and visits to the hospital (which can involve a considerable journey) become less frequent.

Quality of life is an important indicator to us of the success of small bowel transplantation and we ask that you complete yearly questionnaires that enable us to monitor this. You can either do them when you have a follow up visit with us or complete them at home and post them back to us.

**Holidays and vacations**
When you plan a holiday it is important to get adequate travel insurance that includes repatriation should you become unwell when abroad. It can sometimes be difficult to get travel insurance but most reputable insurance companies should be able to help. If you are having difficulty obtaining travel insurance talk to your transplant nurse who will be able to advise you.

**Vaccinations and travel**
If you are planning to travel abroad, check well in advance which vaccinations are required. Immunosuppressed patients should not receive live vaccines.

If you are in any doubt about which vaccines are suitable, please check with the transplant nurse who will be able to advise you.

It is advised to continue having annual vaccinations yearly at your local GP surgery after transplant.

**Taking your medication correctly**
Before your discharge all your medication will be explained to you including when and how to take it. It is very important that you take all your medication as directed and that you do not miss a dose.

You must always ensure that you have enough tablets to last you over bank holidays or if you go away for a short break; in particular your immunosuppressant’s and steroids. You may be asked to change the dose of your immunosuppressants because of the result of a blood test, in which case your coordinator will phone you and recommend either an increase or decrease in dose. It is important that you therefore always have a little extra for these times.

You will be given a post transplant advice book and education on the ward by the small bowel transplant team before you are discharged.

**Eating and drinking**
Following transplant you will probably find that your eating and drinking habits will change significantly.

If you were on PN (parenteral nutrition) prior to transplant you will have got most of your fluid requirements from that and anything you drank will have been purely for pleasure rather than necessity. You may even have been restricted on the amount and type of fluid you drank. Post transplant you will be required to increase your fluid intake significantly in order to maintain your hydration. You may need to drink up to three litres a day, some of which may consist of a rehydration drink called St Marks solution which you can make yourself. It is essentially water with added salt and sugar.
Some people find drinking this amount and type of fluid difficult, but making the effort to do so can help to prevent frequent hospital admissions due to dehydration and the kidney problems that this can lead to.

Similarly, eating may have just been for comfort rather than nutrition prior to transplant so making the transition to having to eat to keep yourself healthy can feel difficult at times. We have a dedicated dietician who will help you make the best diet choices for you.

Some patients report that they have difficulty maintaining their weight post transplant. This is in part due to insufficient calorie intake. We realise that it can be very difficult to change your eating pattern and would encourage you to talk to us about any difficulties you are experiencing. Generally we encourage our patients to eat what they fancy but to keep a record that helps our dietician to identify any gaps in your nutrition and give you supplements that will help.

Supplements come in many different varieties, the most popular being of the milkshake type variety – usually you will find a taste that appeals. Others come in the form of powders that you add to food and fluids that are not detectable when you take them.

**Diet and stoma**

You may find that eating and drinking certain things cause your stoma to become more active. This increased stoma output is not only distressing for patients but can lead to dehydration. In these circumstances we would ask you to keep a record of what you eat and drink to try and identify what may be causing the problem. Together with the transplant team a plan can be formulated to help minimise your stoma output.

**Sexuality**

Having a small bowel transplant can affect your body image. You may not have had a stoma prior to transplant and may worry about how this will affect your personal relationship or if you will have difficulty developing new relationships. You may be scared that you will damage your transplant by engaging in sexual activities. If you have any concerns of this kind talk to your transplant team who will be able to reassure you.

Some patients have considered starting a family post transplant. Our recommendation is that you should not consider this for at least the first year or two post transplant. If it is something you are considering then please discuss with your transplant team. It may be necessary to review some of your treatment and medications and also to refer you to a gynaecologist for a consultation prior to becoming pregnant.

**Mobility**

You have gone through major surgery followed by an extended stay in hospital so your mobility will have been affected. When you are in hospital you will be assessed by a physiotherapist and given assistance required. When you are discharged it is important to take a little exercise to help with your general fitness. Walking and cycling are good gentle exercises. Getting out into the daylight will help boost your vitamin D levels and help your bones to maintain their strength.

**Quality of life**

You may find that your energy levels are not as good as you expected them to be. Some patients report that the combination of medications they are on combined with the need to eat and drink at regular intervals leaves them with very low energy levels.
Social
Spending an extended period of time in hospital can make it difficult to settle back into life at home. In time there is no reason why you cannot get back to your pre transplant social life. In some instances it may have even improved as the health factors that restricted your social life in the past have now been removed.

It is possible to enter into sporting activities although we would recommend avoiding contact sports as this could damage your new organs.

Support networks
A number of our patients have got to know each other well and offer friendship and support to one another. They have set up a support charity called Multi Organ Transplant Support (MOTS). You can contact the group via e-mail at motS2012@hotmail.co.uk or their website www.mots2012.org.uk Please contact our transplant nurses for more information.

This can include the use of drugs such as loperamide (which will help slow up the transit of food through the gut) and avoiding certain foods for example foods high in fat can pass through rapidly. Some patients also report intolerance to lactose so avoiding dairy products may be the answer in some cases.

If you find that you are struggling with your eating and drinking, please talk with the transplant team as soon as possible as we are here to help and support you. As part of your regular follow up we will monitor your weight and diet so will be able to detect if there are any problems and help you to resolve them promptly.

Hospital Chaplain
Should you or your family feel that you or a family member would benefit from a visit from the hospital chaplain at any time between assessment and post transplantation, this can be arranged, please just ask the nurse looking after you or a member or the small bowel transplant team.

Some common concerns post transplant
Returning to work
Most people can return to work approximately six months after their transplant. Obviously this varies according to the work that you do and how quickly you recover. It is better to tell your employer that you will be off work for a realistic period of time and return feeling fit and fully recovered.

Benefits
Many patients have been unwell for the majority of their lives thus unable to work and entitled to benefits. Please inform your transplant nurses if you need any supporting statements to help you with claims.